DOCUMENT RESUME

ED 163 307 CG 012 974

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TITLE Coping with Mental Illness in the Family.
PUB DATE 31 Mar 78
NOTE 20p.; Paper presented at the Annual Meeting of the American Orthopsychiatric Association (55th, San Francisco, California, March 27-31, 1978)

EDRS PRICE MF-$0.83 HC-$1.67 Plus Postage.
DESCRIPTORS *Coping; Emotionally Disturbed; *Family Problems; *Mental Illness; *Psychiatric Services; Research Projects; Residential Programs; *Special Health Problems
IDENTIFIERS *Caregivers

ABSTRACT

Utilizing the conceptual framework of coping theory, 30 family care-givers of mentally ill family members were interviewed to determine the relationship between coping effectiveness and such variables as patient characteristics, factors of the care-givers life situation, and the availability and adequacy of community supports. Care-givers were selected from an earlier questionnaire study of members of a family self-help group. Coping effectiveness was defined as the degree to which the care-giver exhibited emotional mastery, cognitive skill, and personal need fulfillment. It was found that the heaviest burden was felt in the early years of care-taking and on those who attempted to maintain the patient at home. The instrusion of such patients on family life, the constant painful reminder of the illness, and the frustration over lack of effective guidance from professionals were the most frequently stated complaints of care-givers. Families with very ill, chronic, long-term hospitalized patients showed the least sense of burden. They apparently adjusted to the conceptual framework of adaptation and coping appeared to be a promising approach for studying the complexities of such a problem as the one posed in this study. (Author)

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ED163307

COPING WITH MENTAL ILLNESS IN THE FAMILY

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Prepared for the 55th annual meeting of the
American Orthopsychiatric Association
March 27-31, 1978, San Francisco, California

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January 5, 1978

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COPING WITH MENTAL ILLNESS IN THE FAMILY

Recent literature has noted a dearth of research regarding the impact of mental illness on the family. Kreisman and Joy,[5] Arnhoff,[1] Raymond et al, [14] and Marcus[8] note the impact has been inadequately assessed and assume the effects are very profound. Lack of such knowledge handicaps therapists from providing the most efficacious approaches to treatment and the community from developing resources appropriate to family need.

Lasch[6] reports a trend toward re-newed valuing of the family along with a growing disenchantment with public institutions. The assumption of this paper is in keeping with the idea that the family is the primary resource for the patient, whether he is child or adult, and that it is wiser to shore up the family's coping capacities than to make the patient the community's total burden. (Debuskey,[3] Park, [11] Pasamanick et al[12]).

Marcus[8] examined the coping styles of families in his clinical practice and found it a sound and humane way to study families of psychotic children. He points out the depth and complexity of problems faced by these families and advocates devising strategies of intervention that fit the coping style of a particular family. This approach focuses on healthy as well as pathological aspects of family response, their strengths as well as weaknesses.

Theory of psychological stress and coping

Coping theory has served well for conceptualizing the study of many kinds of crises (Hamburg et al.,[4] Mechanic.[9] Parad and Caplan, eds.,[10] Rapoport, [13] and White[15]). It appears to be a very promising frame work for the study of mental illness.

Lazarus[7] defines coping as "problem solving efforts made by an individual when the demands he faces are highly relevant to his welfare" (p. 251). Coping is a form of adaptation made by an individual in response to a fairly drastic change that defies familiar ways of behaving, requires production of new behavior and gives rise to uncomfortable affect. It is an ongoing process aimed toward problem resolution and inner equilibrium. The degree to which the individual has resolved the problem or made adaptive compromise and has regained inner equilibruim is a mark of the adequacy of his coping strategy. According to Lazarus[7], at least three major factors must be assessed if we are to understand how a painful crisis is successfully confronted by a threatened individual:

Situational dimensions. The complexity of most situations make it difficult to ferret out the most influential variables. Certain painful life events - illness, death, dismemberment - predictably produce highly negative responses. Situations that catch an individual off guard, interrupt the flow of his activities and need fulfillment, or leave him in helpless confusion also produce psychological stress. Mental illness is a painful life event; little understood, it baffles and confuses. Its victims behave unpredictably catching those around off guard. Demands on caretakers are constant; little time and energy remain for their personal needs. Novelty, intensity, imminence, and ambiguity are qualities that augment distress,[7] and these clearly describe the schizophrenic syndrome. What meaning mental illness has for the family and to what extent it poses a threat to self-esteem and a sense of competence is another factor in this crisis situation.

Personal dimensions. How an individual responds to threat depends on a number of personality variables:[7]

1. Ways of managing affect. Mastery of disorganizing emotions such as guilt, anxiety, and dispair are necessary to free energy for focusing on cognitive tasks. Ideally the individual uses defenses appropriate to affect management, but minimally distorting of reality.
2. Cognitive resources and skills. A realistic appraisal of the situation, a pattern of information seeking and feedback, a capacity to anticipate events and plan ahead are factors in effective coping. Knowledge, skills, and facilities are needed. It may be in this area that families of mentally ill have been least assisted.
3. Motive strength. To meet serious challenges, persistence, determination, and a sense of competence are invariably required.
4. Need satisfaction met. To cope with extreme difficulty over a long period of time, requires that ones own social-psychological needs are being satisfied. Maintenance of a degree of autonomy and involvement in ego-satisfying tasks are crucial to a feeling of well-being. These are hard to come by when a seriously disturbed person can not safely be left alone.

Dimensions of social support. Caplan[2] emphasizes the importance of others - either the natural community of friends and family or organized professional supports - in helping the stressed individual mobilize his psychological resources.

The Study

This study is an extension of an earlier questionnaire study of 89 care-givers of schizophrenic family members. From the 72 respondents who agreed to be interviewed, 30 were randomly selected. All were members of a self-help group of families and patients of schizophrenia in the Washington Metropolitan Area. The interviews were approximately two hours in length, and, in all but 3 cases, were held in the family's home. The basic question of the study was: To what extent are differences in caregiver effectiveness in coping with schizophrenia related to:

(a) Various patient data - age, sex, length of illness, etc., how his illness is manifested or expressed, and where the individual is being cared for. These were considered the important situational dimensions of this study.

(b) Circumstances of the caregiver's life - age, education, marital status, etc. and the nature of his defense system.

(c) The availability and adequacy of support systems.

The investigator conducted the thirty focused interviews to elicit the above information and to evaluate caregiver's degree of success in coping. Caregiver's questionnair response was attached to the interview data to give a maximally complete picture.

Characteristics of Caregivers and Patients

A summary of Table 1 data indicates this is a select group of families. This must be considered in interpreting the data. Caregivers are female and mothers of high educational level; most are married but not full-time employed; over half are in their forties and fifties. Most families average incomes over $20,000 and live in suburban dwellings.

(Table 1 about here)

There are 32 patients in the study; in two families there are two schizophrenic patients. Patients are disproportionately male, single, and in their twenties. (Table 2) Educational level is high. Most have chronic conditions - over two-thirds have been ill for five years or more. About a third each are in hospitals and in parental homes; seven are in their own homes or apartments, and four live in group homes or residential schools.

(Table 2 about here)

Findings

Questionnaire and interview data for each care-giver were studied to determine level of coping effectiveness. The three component factors - emotional mastery, cognitive skill, and need fulfillment - were each rated separately on a 7 point scale. The average of these ratings provided an evaluation of coping effectiveness. The definitions used were as follows:

Emotional mastery. Degree of optimism about the patient's condition. Relative freedom from crippling anxiety, guilt, grief, and resentment. Defense system adequate to manage emotions but minimally distorting of reality. Nature of affect revealed through speech and facial expression.

Cognitive skill. The degree of realism in appraising patient's illness and prognosis. Amount and kind of information seeking. Capacity to manage disturbing situations. Involvement in planning ahead for patient.

Need fulfillment. Degree of involvement in family and community life. Personal life, fulfilling activities, ego-involving tasks. Life beyond patient management.

Using these as the factors in effective coping, average ratings were made for each caregiver. Three categories were created: (1) High coping ability, (2) moderate coping ability, and (3) low coping ability. Table 3 shows these categories of caregivers in relationship to variables of age and education. Those high on coping success are older and better educated than those who are low.

According to the standards used, the group as a whole showed greater strength in cognitive skill and need-fulfillment than in emotional mastery. This can be interpreted to mean that even though they bear painful responses to this devastation in their lives, they make a strong intellectual effort to know more and to plan for the ill person. This may, in part, be a function of high educational level and time availability. Belonging to a self-help organization is indicative of commitment and search for knowledge that may not be true of other groups in the area.

Patients were rated on a 7 point scale according to their freedom from psychotic symptoms and their effectiveness in functioning. Level of functioning was evidenced by the kind and level of activity they were engaged in, the nature of their social life, and the degree of independence with which they were living. A rating of 7 would indicate essentially normal adult functioning - satisfactory social life, living independently, and involvement in full time work or training. The highest rating of this group, using these criteria, was six. Lowest scores were assigned to those needing full time supervision and whose activities were little more than eating and sleeping.

Table 4 summarizes data regarding caregiver coping effectiveness and patient level of functioning and other patient data. Those most effective in coping have patients that are older, better educated, and that have been ill longer than do those low in coping success. Moderately

successful copers are more like the high in these characteristics.

Contrary to expectations, there is an inverse relationship between level of patient functioning and caregiver's coping effectiveness, e.g., caregivers rated as highest in coping ability have the sickest, least functioning patients. Also, and probably not unrelated, a larger number of patients of high copers live in a hospital - only one lives at home. The largest percentage of patients of low copers live at home.

Care-givers and support systems. It was not possible to establish in this study a clear relationship between effectiveness of coping and availability of informal and professional supports. Histories of patients were too long, and involvement with a great number of resources over time with varying evaluations of them made categorization impossible. By and large these families felt they got sympathy and understanding from relatives, but little practical help. Time often, but not always, resolved family disagreements over patient and growing sibling acceptance. Many named a special friend or relative invaluable to them, although they felt what others could do was, in general, limited. Membership in a group where others shared the same dilemma and where one could turn for help was very helpful.

Caregivers' evaluations of professional services varied a great deal. In general, one was left with an impression of considerable disatisfaction. This may not be surprising since many patients in this study were showing little improvement. Psychotherapy was not thought to be beneficial to patient or caregiver. Caregivers felt professionals were not able to get into their situation and failed to provide them with an understanding of the illness and practical management techniques. Group therapy, often required of them as a part of the treatment of the patient, was almost universally deemed negative. Some felt they were made to feel inadequate and guilty with a net result more destructive than valuable.

Emergency service at home was most frequently, and often most emphatically, stated as a needed service. Interviewees portrayed indescribably difficult and tense situations in which they tried desperately for help as their patient moved toward violence or suicide, ran away from home, or refused prescribed medication and rapidly deteriorated. Some got help through the police and a few through emergency ambulance service; most rode out the crisis or through great effort managed to get the patient to the hospital. "If only someone could come in when things are beyond our control" was a frequent lament. Temporary substitute care was mentioned as needed by those with patients at home, so caregiver could rest and recupurate or take a brief vacation.

Appropriate housing was seen as a real dilemma. But the needs varied from almost total supervision and care to little more than board and room, with all degrees in between. Some patients need considerable help with difficult behaviors, some need motivation to maximum functioning, and some need training in independent living skills. Parents who had explored half-way houses in the area felt they were all operating along similar models, designed for the person functioning well, cooperating with their doctor, and able to work or go to school. Their patients couldn't qualify.

Day care was valued by parents because it got the patient out of the house, but patients frequently disliked it and resisted going. It was very costly for the benefits parents saw, e.g. mainly a place to be.

Discussion

Caregivers having most difficulty coping effectively are those whose patient is deemed well enough to be out of the hospital, but not fully enough recovered to be free from difficult behaviors. The patients are younger, thus less mature, have been ill fewer years, thus giving least time for families to adapt to their disappointments, develop the skills, and learn the resources necessary to managing a mentally ill person at home. Hence these caregivers are suffering more painful emotional tensions, and since they are with the patient daily, have little time to escape and recuperate.

A few examples of families in which coping is especially difficult are in order. One mother of a son in his early twenties states that they are "mentally and emotionally exhausted" as she describes the sense of disorganization, constant motion, and "deliberately annoying" behavior exhibited daily. While having little or no constructive behavior activity, he constantly intrudes on his parents and siblings. He "gets to his mother" so she has been advised by the doctor to work to get her out of the house. The father, in desperation, has resorted to "strong measures" to hold the difficulties down. While psychotic symptoms are medically controlled, he is unreachable about his behavior. They worry constantly about his welfare and his future. The couple have little support from friends or relatives.

Another mother of a son in his mid-twenties, this one still hospitalized, feels depressed a great deal and has dropped all social life because they "never know when our son will be spending week-ends at home." He is in constant purposeless motion and has a history of violence at home and disturbance to neighbors. The mother sees no progress and says the doctor's prognosis is very discouraging. If only he showed an occasional purposeful, meaningful activity it would be heartening to her. Another mother of a hospitalized son can hardly bear to look at her grossly overweight, formerly very handsome

son, whose only activity is compulsive eating and sleeping. Guilt, depression, and resentment color this parent's outlook. Other caregivers lament the lethargy, lack of motivation and future orientation of their children. Parents feel frustrated and baffled because their constant search for new management techniques have little effect on the situation. One mother expressed it as "keeping a thumb on her all the time" or she would relapse into eating and sleeping only. Many parents expressed fears for the future. Some suffered along with their child's depression and lonliness.

A wife of a disturbed man presents an especially devastating picture of the effects of mental illness. Since he is employed and lives in his own home, he fits our category of fairly adequate functioning, but he is difficult in the extreme to live with. He needs constant sound, TV and radio go unceasingly; he is up all night and risks his job by coming in late; carelessness with fire keeps his wife up until he sleeps. She uses his working time to sleep and "rest her nerves." Except for occasional errands and grocery shopping, this is her dreary daily routine. She is constantly depressed and wonders if she can take it much longer. She doesn't know where to turn.

Caregivers showing best coping ability have one of two types of patients: either very chronic, relatively unchanging patients requiring hospitalization or supervised living and thus rarely at home, or a relative showing a high degree of functioning, capable of living relatively independently.

Relatives of the chronically ill over the years have learned acceptance, though not resignation. They continue to search and hope for new treatments for their patient. They all show a high degree of emotional mastery and a capacity to build a life for themselves and their families. They revealed that this did not come easy. They recalled their early reactions as being very traumatic - "like discovering someone had cancer," "shock - frantic search for help - terribly alone," "helplessness - but determination," "utterly confused

and frightened." Slowly they came to terms with the situation, modify their hopes, and rebuild their lives.

Conclusions

The burden of mental illness falls most heavily in the early years of coping and on those trying to cope with the person in the home. Adjusting to the knowledge that one has a chronically ill person, hospitalized and changing little brings its own kind of pain to the family caregivers, but life can go on relatively normally in the home and many of ones satisfactions achieved. When the patient is at home heavily intruding on other family members or effectively doing little but eating sleeping, the problem of adaptation in much harder. There is the constant reminder of the disappointment in their lives and the often fruitless efforts to work toward improvement of patient's functioning and maintaining a kind of balance for the rest of the family.

The commitment these families have to helping the patient is impressive, but for that reason their tensions and frustrations are high. They feel there ought to be ways of working that are better than others, but professionals have little to offer in the practical realm, and writings on management are not existent. New drugs help control symptoms, but little by way of the theory and practice of psychosocial rehabilitation has been developed and even less of that communicated to the primary caregivers. Perhaps, this is the next big challenge to professionals.

To what extent practical know-how together with appropriate allied services may make it viable to keep the patient that home is not known. Certainly, caregivers' frustrations and tensions are going to be high and feelings of inadequacy increased when nothing seems to work, but some might find satisfaction in rehabilitation efforts if they had confidence in what they were doing and experience some success for the heavy energy demands invested.

If in addition, they were valued by professionals as co-therapists for the daily therapeutic efforts they make, and the society around them respected them for their heroic efforts, it might be a more tolerable, even challenging situation.

In many cases, families could cope better and offer more love and support to the patient, if he lived out of the home. But this is possible only if a wide diversity of situations can be created to deal with the custodial or rehabilitative needs appropriate to each patient. It may not require that more services be available - just different ones.

Above all it means a different attitude toward caregivers. The conceptual framework of adaptation and coping provides a better and less judgmental way of viewing them. It involves looking at the total picture including the situational variables as presented by the patient's condition, the particular strengths and weaknesses of the caregiver, and the available supports. Intervention can be made in terms of changes that would enhance the family's capacity to cope more successively.

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Table 1

Demographic Characteristics of Family Care-givers (N=30)

CHARACTERISTIC	
AGE	N
71-80	4
61-70	6
51-60	8
41-50	10
below 40	2
SEX	
Female	29
Male	1
MARITAL STATUS	
Married	26
Widowed	4
Divorced	0
EMPLOYMENT	
Employed	6
Not employed	24

CHARACTERISTIC	
HIGHEST E. LEVEL	N
High School	5
Some College	7
College degree	7
Graduate degree	11
RELATIONSHIP TO PATIENT	
Mother	27
Father	1
Wife	1
Daughter	1
FAMILY SIZE	
No children	1
One or two	8
Three or four	19
Five to seven	2

Table 2

Demographic Characteristics of Patients (N=32)

CHARACTERISTICS	
AGE	N
41-50	7
31-40	5
21-30	15
11-20	5
SEX	
Female	11
Male	21
MARITAL STATUS	
Single	28
Married	2
Divorced	2
PLACE OF LIVING	
Parental home	10
Own home or apt.	7
Group home	2
Hospital	11
Residential School	2

CHARACTERISTICS	
LENGTH OF ILLNESS	N
0-5 years	9
6-10 years	9
11-15 years	3
16-20 years	6
21-25 years	3
26-30 years	2
HIGHEST EDUCATIONAL LEVEL	
Less than High School	6
High School Graduate	8
Some college	9
College degree	8
Graduate degree	1

Table 3

Effectiveness of Coping and Demographic Characteristics of Caregiver (N=30)

	N	DIMENSIONS OF COPING EFFECTIVENESS[a]				AGE[b]	EDUCATION[c]
		Emotional	Cognitive	Need Satis.	Average		
High	9	5.6	6.1	6.7	6.1	59.3	15.4
Moderate	13	3.5	5.6	5.6	4.9	54.4	15.0
Low	8	2.1	3.3	3.0	2.8	53.6	14.1
Average		3.7	5.0	5.1	4.6	55.8	14.8

[a] Based on a 7 point scale with 7 indicating most effective
[b c] Mean age and education

Table 4

Caregiver's Coping Effectiveness and Patient Characteristics

PATIENT CHARACTERISTICS (Mean)	CAREGIVER EFFECTIVENSSS		
	HIGH	MODERATE	LOW
Age of patient	31.1	33.7	22.8
Educational level	13.1	13.6	12.2
Level of functioning[a]	3.1	3.5	4.2
Length of illness	11.7	14.6	7.9
LIVING ARRANGEMENTS			
Hospital	5	3	3
Home	1	5	4
Group home	2	2	0
Own home	2	3	2
SEX			
Male	7	6	8
Female	3	7	1

[a] Based on a 7 point scale with 7 being highest level of functioning